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REGULAR ARTICLE

Lack of knowledge and experience highlights the need for a clear paediatric organ and tissue donation protocol in the Netherlands

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Abstract

Aim: This study explored the attitudes of medical professionals to organ and tissue donation in paediatric intensive care units (PICUs) and neonatal intensive care units (NICUs) in the Netherlands. It also examined their compliance with the existing Dutch donation protocol and assessed whether a paediatric donation protocol was needed.

Methods: We invited 966 professionals working in all eight PICUs and the two largest NICUs to complete an online survey from December 2016 until April 2017.

Results: A quarter (25%) took part and they included PICU intensivists, neonatologists, nurses and other health and allied professionals. Most were female and nurses. More than half (54%) of the PICU respondents considered paediatric organ donation to be very important and 53% supported tissue donation. In contrast, only 22% of the NICU respondents believed that both neonatal organ and tissue donation were very important. Familiarity and compliance with the existing national donation protocol were low. PICU nurses had significantly less experience than PICU intensivists and felt less comfortable with the donation process. None of the NICU respondents had prior donation experience.

Conclusion: Paediatric intensive care units and NICU professionals lack specialised knowledge and experience on organ and tissue donation. A comprehensive and clear paediatric donation protocol is clearly needed.

KEYWORDS

neonatal, organ donation, paediatric, protocol, tissue donation

1 | INTRODUCTION

The waiting list of children requiring organ or tissue transplants grows longer every year, with the constant demand for organs exceeding their supply. This means that some children on the waiting

list die before they can undergo a transplant.¹ Many need size-matched organs from paediatric donors, especially those awaiting thoracic transplantation. Paediatric donors are predominantly children admitted to a paediatric intensive care unit (PICU) and with an underlying diagnosis of trauma, near drowning, cardiac arrest or

Abbreviations: NICU, neonatal intensive care unit; PICU, paediatric intensive care unit.

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neurological disorders. In the Netherlands, there are no age limits for some donations, but the birth weight should be more than 3 kg after brain death for heart, lung, kidney, liver and pancreas donations. The minimum donor age for small bowel donations is 1 year and it is 1 month after circulatory death for liver donations. Heart valve donations are permitted from the time of birth and cornea donations from the age of 2 years. These rules apply to both neonatal intensive care unit (NICU) and PICU patients. The Dutch donation procedure and absolute contraindications for donation are summarised in Figure 1.

A previous study reported that approximately 11% of children who died in Dutch PICUs were potential organ donors and that organs and tissue were recovered from 42% of identified donors.² In particular, it has been reported that paediatric donors who died in PICUs typically succumbed to a hypoxic-ischaemic injury.³ Burns reported that most children who died in PICUs in the United States did so after life-sustaining medical therapy was withdrawn.⁴ Very few donations occur in NICUs. For example, one study of a UK hospital found that only 13% of neonates whose deaths were neurologically determined were thought to be potential neonatal donors.^{5,6} Data on the number of potential neonatal donors are unavailable in the Netherlands.

When a child dies unexpectedly, it has a significant impact on their loved ones, even if they have been receiving palliative care. Paediatric organ donation is a highly sensitive topic for both families and professionals, and there are many barriers. That is why it is crucial to identify potential donors and inform their parents about the donation option in a sensitive and compassionate manner.⁷⁻¹⁰ Barriers to donation include the failure to discuss the issue with families and to notify organ procurement organisations.¹¹⁻¹³ In the Netherlands, PICU intensivists and neonatologists are responsible for approaching the families of potential donors. However, it has been reported that healthcare providers have limited knowledge about the procedural obligations, including the physician's obligation to examine the Dutch Donor Register when a suitable donor aged 12 years or above is found.² Therefore, compassionate, well-informed and competent professionals play a critical role in overcoming these barriers.^{9,14,15} Developing comprehensive and effective protocols and encouraging compliance with them are the possible strategies for enhancing the quality of these rare and complex interventions.^{12,16}

Many countries, including the Netherlands, have introduced organ and tissue donation protocols. The Dutch national donation protocol contains legal and practical information about organ and tissue donation.^{17,18} The protocol aims to provide guidelines for all donation procedures, including neonatal and paediatric donations, but it primarily focuses on adults.¹⁸ The formulation of a specific protocol for paediatric donation may help to eliminate the barriers that can prevent donations by paediatric patients in NICUs or PICUs. Optimising the donation process could increase the number of paediatric donors and reduce the number of children who die while they wait for organs. This study investigated the perspectives of NICU

Key notes

- We explored the attitudes of 245 staff in paediatric intensive care units (PICUs) and neonatal intensive care units (NICUs) to organ and tissue donation in the Netherlands.
- PICU respondents who completed the online survey, from December 2016 to April 2017, were much more likely than NICU respondents to believe donations were very important.
- Familiarity and compliance with the national donation protocol were low, and a paediatric protocol is clearly needed.

and PICU professionals' on donations and donation protocols as a preliminary step towards developing this protocol.

We had three objectives. The first was to assess the attitudes of Dutch professionals in PICUs and NICUs towards organ and tissue donation and to identify work-related factors that influenced their attitudes. The second was to assess compliance with the existing national donation protocol. The final objective was to assess whether there is the need for a comprehensive national organ and tissue donation protocol for children of all ages and to offer relevant suggestions and recommendations.

2 | METHODS

We developed a survey that comprised closed and open-ended questions relating to our study objectives. The Medical Ethical Committee of the University Medical Centre Groningen approved the study and waived the need to obtain informed consent from participants. The survey responses were collected between December 2016 and April 2017.

2.1 | Study participants

All 966 professionals who were likely to get involved in the donation process in all eight of the PICUs in the Netherlands and the country's two largest NICUs were asked to participate in the study. We choose these sites because admissions into NICUs and PICUs varied according to hospitals' policies on age and other criteria. In addition, due to small number of neonatal donations worldwide^{5,6} we decided that only the two largest of the country's 10 NICUs would be invited to take part.

The section of paediatric intensive care of the Dutch paediatric association facilitated the recruitment of professionals in the eight PICUs and two NICUs. Then, a local study coordinator sent out invitations to all professionals who had worked in the units

for at least 3 months. We assumed that all of these professionals have a basic knowledge of organ and tissue donation, as this forms part of the national nursing and medical school curricula in the Netherlands.

The invitation included a covering letter with a link to an online survey containing information about the purpose of the study and how to participate. Participation was voluntary and anonymous. All individual data were kept confidential and used solely for academic purposes. Two reminders were sent, after 6 weeks and 2 months.

Our survey was modelled on Cowl et al,¹⁹ who examined how comfortable and knowledgeable medical staff were with organ donation practices after brain death and circulatory death. We also added specific questions relating to our study objectives.

The survey included questions on individual demographic and occupational data, knowledge, feelings and attitudes towards the Dutch donation protocol and process. We also asked questions about the respondents' experience with the paediatric and neonatal organ and tissue donation procedure. Some of the questions were specific, but we also added open-ended questions to provide a deeper insight into attitudes towards the donation process and the needs for the paediatric donation process. In the final part of the survey, respondents were asked to provide suggestions for optimising the donation process and developing a comprehensive paediatric donation protocol. Appendix S1 shows the survey items. Pilot testing of the survey was carried out by five PICU and NICU professionals, to ensure the questions were suitable and clear and to monitor the time it took to complete the survey. The surveys were then analysed, and the questions were adjusted and retested by the same five PICU and NICU professionals.

2.2 | Statistical methods

We conducted descriptive analyses of the survey responses, describing categorical variables as percentages and numbers. We also applied the Pearson's chi-square test to compare PICU intensivists and PICU nurses, with $P < .05$ being statistically significant. Only completed surveys were analysed. Quantitative data analyses were performed using SPSS Statistics for Windows, Version 22.0 (IBM Corp). The responses to the open-ended questions were analysed thematically by extracting and classifying the recommendations presented in each answer.

3 | RESULTS

Although 43% of the 966 professionals we contacted started to complete the survey, only 245 (25%) of the questionnaires were completed and subsequently analysed. This final response rate was the same for the 162 PICU staff and 83 NICU staff who took part (Table 1). Table 2 shows the characteristics of the respondents. Most of these were nurses—58% in the PICU and 55% in the NICU—followed by PICU intensivists and neonatologists, who accounted for 22% of both the PICU and NICU respondents. Other categories of respondents were general paediatricians, paediatric neurologists or neurosurgeons, fellows, nurse trainees, advanced nurses, social workers and chaplains.

Just over a third of the PICU respondents (35%) considered paediatric organ donation to be extremely important and 54% thought it was very important (Table 3). The percentages of PICU respondents

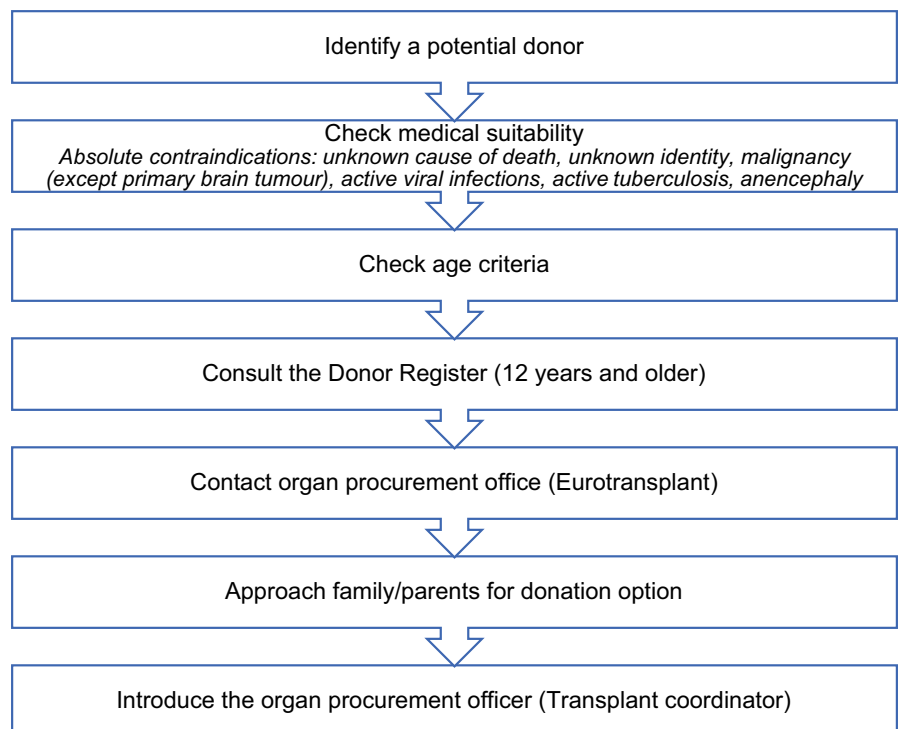


FIGURE 1 Donation procedure in the Netherlands

TABLE 1 Response rates

	PICU	NICU	Total
Distributed	646	320	966
Started	287 (44%)	132 (41%)	419 (43%)
Completed	162 (25%)	83 (25%)	245 (25%)

who considered tissue donation to be extremely important or very important were 21% and 53%, respectively (Table 3).

A breakdown of the attitudes by specific PICU professionals revealed that 56% of intensivists and 29% of nurses felt that paediatric organ donation was extremely important, with a significant difference between them ($P < .001$). The respective numbers for tissue donation were 19% and 22%.

When it came to the NICU respondents, 6% considered neonatal organ and tissue donations to be extremely important and 22% said it was very important (Table 3). In addition, 33% of neonatologists and 22% of NICU nurses considered neonatal organ and tissue donations to be extremely important.

A quarter (25%) of the PICU respondents were familiar with the national donation protocol, 29% were somewhat familiar, 27% knew of the protocol's existence, but were not familiar with its content, and 19% were not familiar with the protocol.

When we looked at specific PICU respondents, this showed that 53% of PICU intensivists and 19% of PICU nurses were familiar with the national donation protocol (Table 4). Most of these respondents felt that the protocol was reasonably clear.

However, 61% of them were PICU intensivists and only 29% PICU nurses consulted the national donation protocol during the donation process (Table 4). The differences between the hospitals were not significant ($P = .811$).

Although 48% of the PICU respondents were sufficiently familiar with organ donation options, only 26% were familiar with paediatric tissue donation options. In addition, 56% of the PICU respondents stated that they had previously checked the Dutch donor registry as necessary (Table 4).

A third (33%) of the NICU respondents were familiar with the neonatal organ donation options and 31% claimed a sufficient level

Respondents %		Profession %		Gender %		Work experience median (years)
PICU 1	16	Nurses	58	Male	17	11
PICU 2	8	PICU Intensivists	22	Female	83	
PICU 3	16	Other health				
PICU 4	8	Professionals*	17.5			
PICU 5	12	Allied				
PICU 6	7	Professionals**	2.5			
PICU 7	26					
PICU 8	7					
NICU 1	40	Nurses	55	Male	16	12
NICU 2	60	Neonatologists	22	Female	16	
		Others health				
		professionals	18.2			
		Allied				
		professionals	4.8			

*Other health professionals: general paediatricians, paediatric neurologists or neurosurgeons, fellows, nurse trainees, advanced nurses.

**Allied professionals: social workers and chaplains.

TABLE 2 Respondents' characteristics**TABLE 3** Attitude towards organ and tissue donation

	How important for you is donation?				
	Extremely (%)	Very (%)	Moderately (%)	Not very (%)	Not at all (%)
Paediatric organ donation (n = 162)	35	54	11	0	0
Paediatric tissue donation (n = 162)	21	52	25	2	0
Neonatal organ and tissue donation (n = 83)	6	22	49	21	2

TABLE 4 Self-assessed familiarity with protocol and options

Sufficient familiar with:	PICU intensivists (n = 36) %	PICU nurses (n = 94) %	Neonatologist (n = 18) %	NICU nurses (n = 46) %
National protocol	53	19	0	2
Options regarding paediatric/neonatal organ donation	81	35	50	28
Options regarding paediatric/neonatal tissue donation	50	17	61	17
Types of donors (DBD and DCD)	83	45	100	37
How the Donor Registry operates	81	41	NA	NA
Consulted national donation protocol in practice	61	29	NA	NA

Abbreviations: DBD, donation after brain death; DCD, donation after circulatory death.

of familiarity with neonatal tissue donation options. However, only 2% of these respondents were familiar with the Dutch donation protocol, while 13% were somewhat familiar with it.

More than 92% of PICU intensivists and 65% of PICU nurses had previous experience of the paediatric donation process. Those PICU staff with paediatric organ donation experience had mostly been involved in donations after brain death. Only 15% had prior experience with paediatric tissue donation.

There was considerable variation in PICU respondents' comfort levels regarding the donation process (Table 5). Most PICU intensivists who were involved in the donation process felt highly or moderately comfortable with the donation process and most PICU nurses felt moderately comfortable. The findings further indicated that the difference between PICU intensivists and PICU nurses was significant ($P < .001$), with intensivists expressing a higher level of comfort with the donation process.

Some respondents who experienced obstacles during the entire donation process made critical remarks about this process, such as a time path of the donation process and staff lack of knowledge about donation.

Most respondents felt that the type of donation influenced the donation process. More than half (59%) of the PICU respondents said it was different when children who already were receiving palliative care were suitable donors. They specifically said that the process of

saying goodbye to them was different for their families, compared with those whose children were not donors.

None of the NICU respondents reported previous experience of neonatal organ or tissue donations. However, 44% of the neonatologists and 26% of the NICU nurses had been asked by parents about the option of donation and most of them felt comfortable about discussing this subject.

Paediatric intensive care units respondents generally agreed that an optimal donation process involved good communication, collaboration, knowledge and providing the parents with adequate information. One respondent said: '*Clarity, honesty and open communication are required. It must be made very clear to parents what the options are and what they can expect. For this, it is necessary to talk about organ donation at the right time. Mutual expectations should be clarified. The impossibilities, but especially the possibilities, should be clearly discussed. For this, the nurse, doctor and donor coordinator are important.*'

Respondents also provided suggestions for developing a comprehensive paediatric donation protocol. They highlighted issues that they felt needed to be considered, such as: suitability for donation, types of donation, donation process and approaching the parents.

Respondents recommended including the following aspects of palliative care in a protocol: support for the parents and family, after-care and ensuring that parents can say goodbye to their child. They

TABLE 5 Feelings about the donation process

	How comfortable are you with the donation process?				
	Extremely %	Very %	Moderately %	Not very %	Not at all %
All PICU respondents (n = 162)	4	27	60	10	0
PICU intensivists (n = 36)	14	50	28	8	0
PICU nurses (n = 94)	3	21	55	16	2

felt that the last point was essential. They also recommended including allied health professionals, such as chaplains or social workers, in the care of potential donors and their families.

About 70% of the PICU respondents endorsed anonymous sharing of experiences and cases with other colleagues, with a significant difference ($P < .003$) observed between intensivists (53%) and nurses (79%).

4 | DISCUSSION

We investigated the attitudes of PICU and NICU professionals regarding paediatric donations and their compliance with the national protocol.

Our findings showed that professionals working in the PICUs considered paediatric organ donation to be an important issue. Almost all of the intensivists and 65% of the nurses in the PICUs had prior experience in organ and, or tissue donation. Our finding that PICU nurses had significantly less experience and lower comfort levels during the donation process compared with PICU intensivists is an important one. A possible explanation for this difference may be attributed to the rarity of paediatric donations^{1,2} together with large nursing teams that had a relatively high turnover. Moreover, whether PICU nurses got involved in donation cases depended on the specific patients they were caring for and this meant it was a rare occurrence. In contrast, the intensivists while on service were involved in all PICU donations. As a consequence, the nurses' experiences of the donation process were likely to differ. These results were in the line with studies that demonstrated that nurses were less involved in the donation process and their lack of experience made them less confident and more uncomfortable with the donation process.²⁰⁻²³ They also had a greater interest in sharing experiences and cases with colleagues than the intensivists and this could be attributed to their lack of experience.

We found low levels of self-reported knowledge and compliance with the existing national donation protocol, which is a cause of concern.

A further aim of our study was to evaluate the need for a paediatric donation protocol. The responses we obtained for the open-ended questions supported the need for a comprehensive and clear step-by-step paediatric donation protocol that is easy to follow and implement. Such a protocol should support health professionals to routinely give parents the opportunity to think about organ and tissue donations and make a decision. Darlington et al found that this was important to the parents of children who died in the PICU and NICU, who took part in an empirical data study.²⁴ In addition, respondents lacked practical knowledge, which indicated the need for more education about palliative care for potential donors and aftercare for parents. In line with our findings, previous studies have demonstrated that more education about donation is needed.^{20,23}

Our findings suggest that knowledge about the existing protocol and the possibilities of neonatal donation among NICU respondents

was lacking. This finding was partly in the line with the findings reported in the literature on neonatal donations in 2014,⁶ but it was also partly unexpected, because some parents reportedly asked direct questions about the option of donation. In addition, none of NICU professionals had donation experience. NICU professionals evidently need education about the donation protocol and, in particular, the practical possibilities for neonatal tissue and organ donation. We believe that neonatal organ and tissue donation should be a component of paediatric medicine.

The study had some limitations. First, because the survey was conducted online, partially completed surveys could not be saved. Although the reasons for non-responses were not known, the response rates may have been reduced because this feature was not available. A second limitation was the issue of bias in self-reporting, which can influence knowledge ratings. Finally, more than 15% of the respondents were other health professionals, namely physicians, fellows, nurses trainees or advanced nurses. Their involvement in the donation process, and how this may have influenced the results of this survey, was unclear.

5 | CONCLUSION

Paediatric organ donation is important topic among Dutch PICU and NICU professionals. Although compliance with the existing national donation protocol was low, the professionals lacked specialised knowledge and training regarding paediatric organ and tissue donations. PICU nurses had significantly less experience than PICU intensivists and felt less comfortable during the donation process. None of NICU professionals had experience of actual donations, but some had been involved in discussions with parents about the option of donating. There is evidently a need for more guidance on the paediatric donation process, such as a comprehensive donation protocol that covers all paediatric donation issues. The implementation of a comprehensive paediatric donation protocol should include education about the protocol and the donation process for all PICU and NICU professionals.

CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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